

We are still gay ...



AN EVIDENCE BASED RESOURCE EXPLORING THE EXPERIENCES AND NEEDS OF LESBIAN, GAY, BISEXUAL AND TRANS AUSTRALIANS LIVING WITH DEMENTIA

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**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**
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Foreword

Lynda Henderson lesbian advocate/care partner

This resource is an example of pioneering action research: it points the way forward to meeting the real needs of LGBTI people living with dementia. It will be invaluable as a staff training resource for service providers wanting to actively engage with the diversity of their clients. It will also assist advocacy organisations to raise public awareness of the issues experienced by LGBTI people living with dementia. As a lesbian advocate/care partner of someone living with dementia, a member of the Kiama Dementia Friendly Community Advisory Group, and as a training and development consultant I highly recommend it.

Carol Bennett CEO Alzheimer's Australia

Alzheimer's Australia represents more than 342,800 Australians living with dementia, the estimated 1.2 million Australians involved in their care and the 10% of these cohorts expected to be LGBT. The role of Alzheimer's Australia is to advocate on the basis of evidence-based policy. We therefore are pleased to partner with Val's Café at the Australian Research Centre in Sex, Health and Society, La Trobe University in the development of this first evidence base on the needs of LGBT Australians living with dementia. This resource will promote awareness of the experiences and needs of LGBT people living with dementia and help to ensure that they are respected, supported and empowered. The stories in this resource are compelling and demonstrate the importance of focusing on the voices of consumers. We hope that dementia and aged care services around the country will take up this resource. We look forward to considering these findings when progressing the aged care reforms.

Rowena Allen Commissioner for Gender and Sexuality Victoria

Our LGBTI Elders have lived a period of great change in Australia. Their lives have been shaped by criminalisation, stigma and discrimination, which they have faced with perseverance, resilience and dignity. They have also been instrumental in many of the recent, profound moves towards equality that we now take for granted. Ever pioneers, they are now, not by choice, highlighting the need for greater LGBTI inclusion in dementia and aged care services. This report, for the first time, gives us an opportunity to hear the voices of these Elders, both those living with dementia, and their partners. It is also a timely reminder that dementia can commence at any age. I urge service providers to follow the recommendations in this report, so that our Elders no longer have to work alone to achieve equality and justice. LGBTI Elder deserve our care and support, we owe them a great debt. I would like to congratulate Val's Café and Alzheimer's Australia for the partnership that led to the development of this resource. It is the first time these voices have been heard, and it's an important first step in ensuring better health care for LGBTI Victorians.



Table of contents

SECTION 1: INTRODUCTION.....	6
BACKGROUND.....	6
Historical treatment of LGBT Australians.....	6
The effects of discrimination.....	6
Legislative and policy reforms.....	7
HOW TO USE THIS RESOURCE.....	7
SECTION 2: KEY ISSUES AND STRATEGIES.....	8
SECTION 3: STORIES.....	10
STORY 1: ANNE AND EDIE - SEXUALITY IS NOT A RINSE COLOUR.....	10
STORY 2: DALE AND LILLIAN - AN IMPRESSIVE MIND.....	12
STORY 3: GREG AND KEVIN - IT'S THERE IN FRONT OF YOU.....	14
STORY 4: GAVIN AND RICHARD - TAKE US OR LEAVE US.....	16
STORY 5: NICK AND GEORGE - OUR NATURAL SELVES.....	18
STORY 6: TIM AND PHILLIP - SOMEWHERE FULLY NICE.....	20
STORY 7: JEREMY - IF I COULD GO OUT THE FRONT DOOR.....	22
STORY 8: GEOFF AND DAVE - NOT BEING DIFFERENT.....	24
STORY 9: LYNDA AND VEDA - A RED AND BLACK ANGRY SKY.....	26
STORY 10: MAURICE AND COLLIN - IF YOU DON'T UNDERSTAND – ASK ME.....	28
STORY 11: EDNA - FOR HARVEY, HE'S A WOMAN NOT A MAN.....	30
SECTION 4: RESOURCES AND FURTHER INFORMATION.....	32
REFERENCES.....	32

Section 1: Introduction

This resource draws on two studies conducted by Val's Cafe at the Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University. The first was an LGBTI Dementia project conducted in partnership with Alzheimer's Australia to document the experiences and needs of LGBTI people living with dementia (1, 2). The second was a Trans Ageing and Aged Care project conducted in collaboration with the Gender Centre NSW, Transgender Victoria and FTM Shed to document trans people's experiences of ageing and aged care, including their experiences of dementia (3). Both studies took place between 2014 – 2015 and involved interviews with 32 lesbian, gay, bisexual and trans (LGBT) participants. No self-identified bisexual, trans or intersex people were recruited for the Dementia Project. Interviews were also conducted with six aged care service providers after they contacted the research team to discuss the care needs of trans clients. The research team included three researchers from ARCSHS and one from Alzheimer's Australia New South Wales. The shared expertise in sexuality, ageing and dementia was critical to the success of this project.

This research is pioneering – the needs of LGBT Australians living with dementia have not previously been researched. In doing so we have gained new insights and have the opportunity to improve dementia and aged care services.

This resource is part of a LGBT dementia tool kit developed from the research. The tool kit also includes early findings from the research (1), a full research report (4) and a film (5).

This resource includes four sections. In the current section we briefly outline historical and legislative factors influencing the needs of LGBT people living with dementia. We also present suggestions for using this resource for education to build a basic understanding of LGBT histories, health and wellbeing essential to fully appreciate this resource. In Section 2 we provide an overview of the key issues arising from the research and suggest strategies for addressing these. Section 3 presents 10 stories from the participants in their own words and each story is accompanied by questions that can be used for discussion and education. The final section lists additional resources.

Background

Historical treatment of LGBT Australians, the impacts on health and wellbeing and recent legislative and policy reforms provide important context for this resource. These are outlined below and we recommend a series of Guide Sheets to provide readers with further information (6).

Historical treatment of LGBT Australians

Older LGBT Australians have lived most of their lives aware that disclosing their sexual orientation or transgender identity could result in arrest and imprisonment, psychiatric incarceration and enforced attempted 'cure' treatments (7). Disclosure could also result in the loss of family, friends and employment (7). The effects of these historical experiences are not limited to a particular age cohort. Rather, they continue to shape the way we interact with LGBT people, regardless of their age.

The effects of discrimination

The experience of growing up in homophobic and transphobic societies has contributed to higher rates of depression and anxiety among older LGBT people (7,8,9) and LGBT people more broadly (10). It also resulted in the onus of responsibility being placed on LGBT people to conform to sexuality and gender norms in order to avoid upsetting the status quo (7). This sense of responsibility has persisted across the life span and some LGBT people still believe their sexual orientation or trans gender identity should be hidden to avoid confronting others (11). For some, intimate relationships and friendships with other LGBT people represents the only place they feel safe or able to be themselves (7,11).

Legislative and policy reforms

Recently there have been significant reforms recognising the rights of older LGBT Australians (6). These reforms include the development of a National LGBTI Ageing and Aged Care Strategy in 2012 (12). The Strategy describes the Government's commitment to ensuring the needs of older LGBTI people are understood, respected and addressed in Australia's aged care policies, programs and services. It identifies responsive dementia assessment and care as a key action area and makes explicit reference to the importance of ensuring that dementia services are inclusive of and responsive to the needs of LGBTI people (12). The Strategy also highlights the need to "empower older LGBTI people as self-advocates and experts to be consulted about their own ageing and aged care needs and circumstances" (12, p.16). In drawing on these principles of empowerment we privilege the expertise and voices of LGBT people living with dementia.

How to use this resource

This resource has been developed to provide service providers with an evidence base on the experiences and needs of LGBT people living with dementia. By doing so we hope to promote the development of LGBT inclusive services for people living with dementia. It should be used for education in conjunction with more general information about LGBT ageing and aged care. The following table outlines a step by step interactive education program that encompasses general and dementia specific information. It is important that facilitators familiarise themselves with the information in all 6 steps and tailor education to the learning needs of their audience. The duration of education may vary from 2 hours to a full day or series of workshops and can include staff, volunteers or carers. All the resources in the following table are available on the Val's Café website.

Step	Suggested Use
1. Terminology	<ul style="list-style-type: none">• Read the Aged Care Assessment Service LGBTI Inclusive Guide Sheets (see reference list) to familiarise yourself with commonly used terms
2. History and its impacts	<ul style="list-style-type: none">• Watch the Then and Now films (see valscafe.org.au)• Read narratives in the My People My Story resource (see valscafe.org.au)• Read stories in the No Need to Straighten Up report (see reference list)• Discuss the historical treatment of LGBT Australians and how this might impact on the experiences of LGBT people living with dementia and their intimate partners• Discuss how historical perceptions of LGBT people might still influence the attitudes and beliefs of service providers and clients in shared services
3. Legislative and other reforms	<ul style="list-style-type: none">• Read the Aged Care Assessment Service LGBTI Inclusive Guide Sheets to familiarise yourself with relevant legislative and other reforms• Read the National LGBTI Ageing and Aged Care Strategy (see reference list)
4. Principles of LGBTI inclusive aged care	<ul style="list-style-type: none">• Rate your service using the Val's Café Self Assessment and Planning (SAP) Tool (see valscafe.org.au)
5. Key issues and strategies for LGBT people living with dementia	<ul style="list-style-type: none">• Read the key issues and strategies outlined in Section 2 of this resource and discuss how these strategies will be implemented in your service.
6. The lived experiences of LGBT people living with dementia, and their intimate partners	<ul style="list-style-type: none">• Read stories in Section 3 and discuss using the questions provided• Watch Edie: One day in the life of a lesbian with younger onset dementia (see reference list)

Section 2: Key issues and strategies

In this section key issues from the interviews are presented alongside strategies to meet the needs of LGBT people living with dementia

Sexual orientation

Being lesbian, gay or bisexual was described as a fundamental aspect of personhood that endured beyond the diagnosis of dementia. The failure to recognise sexual orientation or same sex relationships negatively impacted on the wellbeing of LGBT people living with dementia and their intimate partners. *It is important that service providers recognise the sexual diversity of people living with dementia.*

Transgender identity

Some trans people living with dementia required support to maintain their gender identity and this support was not always provided by family members or service providers. *Gender identity needs to be recognised as a fundamental human right and support provided to enable people living with dementia to maintain their preferred gender identity.*

History and onus of responsibility

Participants reported fears that discrimination still occurred. There was a sense of responsibility to manage disclosure of sexual orientation or gender identity to escape discrimination and also to avoid making others uncomfortable. *It is important service providers understand that history has diminished some LGBT people's sense of entitlement. It is also important to be mindful of historical experiences of discrimination when undertaking assessment or developing life stories. Questions about experiences growing up, family and early relationships may precipitate anxiety or be re-traumatising.*

Fear of discrimination

Some LGBT people fear that dementia will make them vulnerable to homophobic and transphobic abuse, particularly from service providers. This resulted in delay or refusal to access services they needed. *Service providers could significantly address the fears of LGBT people living with dementia by demonstrating their commitment to providing LGBT inclusive services.*

The nature of disclosure

The fear of discrimination resulted in some LGBT people hiding their sexuality, transgender identity, body and/or relationships. This in turn resulted in participants not fully disclosing their needs. *Service providers who demonstrate LGBT inclusive practice will communicate to LGBT people living with dementia and their intimate partners, that they are aware of the importance of providing a safe spaces for full disclosure of needs.*

Managing disclosure

Many LGBT people survived historical experiences of discrimination because they learned to determine when and with whom it was safe to disclose their sexual orientation or transgender identity. Managing disclosure in this way required a significant level of cognitive function that diminished with dementia. The fear of inadvertent disclosure was a source of stress for some LGBT people living with dementia and intimate partners. *Service providers who are aware of the fear of inadvertent disclosure can alleviate anxiety by communicating that they are LGBT inclusive.*

Acknowledging intimate relationships

Intimate relationships held particular significance in the lives of LGBT people living with dementia. The relationships provided a protective space against discrimination and a place where diversity was affirmed. Despite this, intimate partners were not always recognised by families of origin or service providers. This was particularly distressing for LGBT people. *It is important that service providers recognise and respect the diversity of intimate relationships.*

Intimate partners as carers

The fear of discrimination in services resulted in LGBT people living with dementia delaying or refusing to access services. Some couples promised to take care of each other at home to avoid services they feared would discriminate. Many didn't have children or families of origin for support. The heavy reliance on intimate partners adversely impacted on carer physical and mental stress. *Service providers need to demonstrate they are LGBT inclusive in order to build the confidence of LGBT people who require support.*

Carer groups

Carer groups were reported to provide a valuable source of support. However, some LGBT carers did not feel welcome in groups where heteronormative assumptions were made about their lives and relationships. *The facilitation of carer support services need to take into account the diversity of carer sexual orientation and gender identity to ensure groups are accessible to all carers.*

Families of origin

Participants who described earlier conflict with their family of origin reported being vulnerable to further abuse as their dementia progressed. The process of working through conflict with family of origin re-traumatised LGBT people living with dementia and their intimate partners who were already experiencing carer stress. *Service providers who understand the historical tensions that occur with some families of origin and the legal rights of LGBT people are well placed to recognise the emotional difficulty of such conflicts and advocate for the rights of the LGBT person living with dementia – particularly those who don't have an intimate partner.*

Activity programs

Accessing activity groups or events provided important opportunities for LGBT people living with dementia to socialise and provided respite for their partners. However, heteronormativity in these services was described as a barrier to engaging the interest of LGBT people living with dementia. *There is an opportunity to engage with LGBT people living with dementia to ensure activity and event programs are not heteronormative.*

Social connection

Being socially connected to LGBT communities was reported to enable LGBT people living with dementia and their partners to 'be themselves', 'speak freely' and feel understood. Social connection is linked to improved health and wellbeing and therefore the loss of these social networks was particularly upsetting. *There is a need to educate LGBT communities on the importance of reaching out to support community members living with dementia, particularly those without an intimate partner. There is also an opportunity to inform LGBT people living with dementia about LGBTI specific community visitors schemes (where these exist) and the important support they can provide.*

Grief

The death of an intimate partner who had lived with dementia was described as particularly difficult. Grief was expressed in relation to the loss of companionship, the discrimination and difficulties encountered, the lack of recognition by families of origin and the loss of LGBT community connections. *There is a need to recognise and support intimate partners after the death of their partner. This support is particularly important for those who are socially isolated and others whose experiences and relationships have not been validated.*

Going it alone

Many participants described the importance of advocacy. Some were skilled self-advocates and others worked hard to advocate for their partner who was living with dementia. There was an awareness that advocacy was required to ensure rights were not violated, and to prevent homophobic or transphobic abuse. In reflecting on this, a number of participants expressed concerns for LGBT people who did not have a partner to advocate on their behalf. *Service providers are well placed to identify LGBT people living with dementia who do not have an advocate or supports. Service providers have a key role to play in ensuring needs are identified and supported and their rights are respected.*

Powers of attorney

Some families of origin and service providers did not recognise the legal rights, authority or expertise of LGBT people's intimate partners. Several participants reported that their application for power of attorney to make decision for their intimate partner, who was living with dementia, was contested by homophobic or transphobic families of origin. While the legal rights of intimate partners were upheld, the challenge and claims made by family of origin caused significant distress for intimate partners at a time when they were under resourced. *LGBT people with dementia may benefit from documenting powers of attorney (legal documents describing who can make decisions for them) to ensure their dignity and rights are upheld. Developing and allocating powers of attorney as early as possible may assist in minimising conflict and is particularly important for those 'going it alone' without an intimate partner.*

Advance care planning

Some trans people reported having spent their life educating service providers and family members about their gender identity and health care needs and wishes. With dementia the loss of capacity to do this made them vulnerable to transphobic family members and service providers. *Documenting future health care wishes in an advance care plan is a useful strategy for all LGBT people, and trans people in particular, to ensure their needs are understood and wishes are respected when they are no longer able to communicate their needs and wishes.*

When reading the narratives in the following section, we invite you to reflect upon and consider the key issues and strategies outlined above, and determine appropriate responses for your service or organisation.

Section 3: Stories

This section outlines 10 stories from interviewees, in their own words. At the end of each story we have suggested questions that could be used to guide discussion with service providers. Please consider the key issues and strategies as outlined in the previous section.

Story 1: Anne and Edie - Sexuality is not a rinse colour

“People with dementia disconnect, there are lost connections, but something that’s as fundamental as your sexuality is not going to change.”

Edie and I have had an amazing journey. From the first moments we got together over 30 years ago there has been absolute trust. Whereas in a previous relationship, that wasn't the case. So, you know, the common interests and values were always there but we're also very different people and so over the years we've both learned so much from each other, you know, like we've brought the best out in each other and also we've both done a lot of personal psychotherapy. You know, there's stigma associated with dementia and Edie and I grew up in a time where there was certainly stigma associated with being lesbian and gay.

So I think when people are working with older people who are gay or lesbian they need to ask themselves what their perception of a gay person. There are many people who have a reserve or a cautiousness or they don't understand us, there is a discomfort that's not expressed. And I think that's where the stigma is. The stigmas around: I'm not familiar with this, I don't understand it, there must be something wrong with them. Why are they like that?

It's a double whammy. If you have dementia and if you happen to be gay or lesbian, I think it's a double whammy where people do need to know what their true attitudes are.

We have friends, a lesbian couple and one of them is dying of cancer. And that's really interesting because they get incredible support. People are always dropping round meals and contacting them - but we don't get that. Dementia is a terminal illness but you don't have to take steroids so you don't have that really awful look. It's more what's going on in your brain. I've found at times people sort of don't know what to do or they don't know what to say, you know. It's an indeterminate sentence. You know, a really close lesbian friend was diagnosed with cancer at 55 and she's dead at 59 years of age. Edie's disease is progressing much more slowly than all the other people we know.

There is a lesbian couple we used to classify them as good friends but we don't now because we really don't see them. I think maybe they were good friends when we could all do things together. But we don't go out at night now, Edie gets very tired. You can't do what you used to be able to do and you fall out of the loop. So our social life is very, very limited now and it revolves around close family and a few close friends. Some people are just extraordinary in their understanding and support.

The ones that you've got left are so important to you but a lot of people drift away. You've got to put time and energy into relationships, I don't have that time and energy.

A lot of people don't want to know about it, they don't get the diagnosis, don't want to get the diagnosis. We certainly don't know of any other lesbians with dementia. It'd be nice if we did.

Carer partners make no judgments, they're all very comfortable because we're all in the same team in a sense. We're all battling the same thing and so you're just trying to keep your head afloat in dealing with it. There's an acceptance and a genuine warmth there and understanding. Dementia seems to transcend negative attitudes to sexuality you know. Again, I'm saying the closer you are to the issue the more it's a non issue.

There's a real warmth and comraderie amongst these people because you all have an understanding of what each other's lives are like. But to actually have, you know other women or men who were gay in your circle, you've got that additional aspect in common.

As part of their training they must learn a lot about basic human needs and respecting people and treating them with dignity and so forth. But a lot of older people get mistreated and abused in these nursing homes and, you know, they get ignored and I think those people have to be flushed out.

It's up to the organisations to make sure that the people that they employ are the sort of people that are there to not judge anyone. And to give that personal quality of life that they deserve and that they're entitled to. So, I think that their attitudes towards their cultural background, you know, the language they speak and their sexuality, all of those things, should be assessed to ensure they are appropriate for such important work.

The suggestion someone would turn straight - you may as well say hippopotamuses turn pink when they get to age 70. That suggestion is also assuming that the natural state is straight and that somehow or other we all get back there. But there are lots and lots of reasons why gay and lesbian people with dementia wouldn't turn straight.

There could be an argument for people becoming less sexual or more asexual in the sense that they're not looking to have an active sexual life. But the idea that you spend all your life being more attracted to women then that is no longer the case and that you're now drawn towards men is such a nonsense.

You know, it's probably one of the most absurd things I've ever heard of and I'd be incredibly surprised, amazed even because what that suggestion implies is that Edie will turn away from what she's been all her life and who she's been with most of her life and go to something that was unnatural for her. People with dementia disconnect, there are lost connections, but something that's as fundamental as your sexuality is not going to change.

It's who you are. You know, it's like - it's not a cloak you wear. You know, it's not a rinse colour that you put through your hair. It's fundamental, you know, to who you are and how you relate to people.

I was Edie's first partner - first and last I hope, unless you go straight on me Edie.

Edie: I don't think that will happen.

Anne: No, I've got absolutely no fears of that at all.

Edie: No, you're pretty safe darling.

Questions for discussion

1. What do you think a 'double whammy' means in relation to lesbians who are living with dementia?
2. What changes to their relationship do Anne and Edie describe?
3. How might service providers communicate respect for same sex relationships?
4. How might your organisation communicate that staff have put aside any negative preconceptions of LGBT people?

Story 2: Dale and Lillian - An impressive mind

My name is Dale and I was born in 1943. My partner Lillian was born in 1937. We were together for 20 years. The most impressive thing about Lillian was her brain. She had a first class honours degree and her thesis had been on aged care. She was a great advocate of leaving people in their homes and supporting them.

"A care worker used to talk to me about "people like you". I didn't know what she was talking about ...so I finally latched onto what she meant...that I am a lesbian."

Lillian's children turned their backs on her. Before she was diagnosed it was always Lillian who went to see them and they visited her once a year as a rule. But after she was diagnosed the children never visited, never sent her birthday or Christmas or Mother's Day Cards, they never even rang to ask how she was.

As Lillian's condition worsened they just wanted to be in control and they didn't want me to be in control. That's how I read it. It was all about me, not about looking after their mother. The fact is they didn't give a fig, but they're all standing in line now waiting for the Will to be read. The next thing I know I am summoned to the Guardianship Tribunal. So I lost control of access and accommodation for a year, and I lost control of Lillian's finances forever.

After three or four years of being the sole carer I had to get help. I was really in serious trouble by then in terms of physical labour. It was very demanding. So an EACH-D (extended aged care in the home – dementia) package was taken up and in home care provided by one of the organisations that service this area. And that's when we really had problems. Lillian's anxiety continued because of the irregular and unpredictable care worker schedule and roster, and she stopped weeing and developed a severe urinary tract infection. So I employed someone privately.

Some of the care providers assumed Lillian was my mother. They would say "Oh is your mother sick is she", or "your mother's got dementia". And I'd say it's not mother, she's my partner. They were very proper, you know, church going ladies.

One of the care workers used to talk to me about "people like you". I'd forgotten all about that. "People like you", she said. I didn't know what she was talking about at first. People like me; you mean intelligent or well read? So I finally latched onto what she meant, the fact that I am a lesbian. She was a strange piece of work; even the service providers knew she was a bit odd. I can't remember which organisation she came from.

It was always church based service providers servicing the EACH-D. The non-church ones, as far as I could make out, don't service here. So we don't have a lot of choice, not much choice at all. I was concerned about the church based services because I thought they'd come with prejudice. I thought they'd come with attitude.

I can't say their prejudice was upfront but I'm fairly sure it was there in the background. I would look in the paperwork to see whether I was described as a partner or carer, but they didn't falter on that front filling in the forms. But you don't know what's in the backs of people's minds.

I went to a carer support group and it was fantastic, great stuff. There might have been some people biting on their tongues about the fact I was a lesbian, I don't know, but it didn't bother me because I didn't notice it. But nobody left the room. I think there's enough out there in public about same sex couples that I think you'd have to go a long way to find somebody who'd react.

I was the only one in our carers support group who was still caring at home and I'm the only one in the group who cared at home until death. For me it was the better choice from the point of my conscience and being true to her, but also in terms of convenience because otherwise I would be worrying, having sleepless nights. And I have to live with myself afterwards, so I had to have a good conscience about it. So that's why it happened. There might have been a time when it became impossible but it didn't, Lillian died before it was impossible. It got very close though.

Something I fear down the track is if you have to go into a facility and you're on your own, you don't even have any like-minded people. You might as well just pull the plug, you know. It would be just awful.

I have a couple of friends who stayed with me the entire time I was caring for Lilian. But some of my friends dropped off, maybe because I didn't have the time or energy to stay in touch. But the other side of it is you find that people who would normally drop in for a coffee and a chat stop doing that, and my reading of this is that they don't know what to do, so they stay away.

When Lilian died, suddenly they were all knocking on the door and ringing me up, "Hey, how about a cup of coffee. How about coming out to dinner, how about..." It buggers you up a bit.

And so when it was all over I crashed, I came down with the flu. I was sick for months after Lilian died. Finally, I'm okay. Finally. I think I'm okay. I haven't gone out yet.

The whole experience is still in the foreground of my life. I know it's happened and it's affected me but I haven't come to terms with it. I've always thought of myself as an onion and I just keep growing skins around things. I haven't grown the skin around it yet, or the bark on a tree.

Questions for discussion

1. How does Dale describe the impacts of the application for Guardianship on her?
2. Why do you think Dale cared for Lilian at home for so long?
3. What assumptions did service providers make about Dale and Lilian's relationship – and how could such assumptions be avoided?
4. What do you think the care worker meant by 'people like you' – and what impact might such statements have on LGBTI people?

Story 3: Greg and Kevin - It's there in front of you

Greg: In 2006 we were first diagnosed. It's been frustrating. I get halfway through the conversation if it is interesting and I lose the focus on it.

You don't stop being gay if you get dementia. Naturally you are still gay. Saying I would become straight is being stupid, because for a person being gay is part of your life, a part of your make-up. No, we can't make being gay disappear, it's there in front of you.

"We have a few lesbian neighbours. I think it's important to mix with gay people because you can freely speak I suppose. Like me saying we don't flaunt our sexuality but when you're mixing with your own type, you speak freer."

Kevin: Greg and I have been together for nearly 40 years. I'm 75. We have never been the type to flaunt our sexuality. If anybody asks, yes, they're told. The people looking after us have never questioned or asked flat out are we gay. We have quite a few lesbian neighbours, we look after them, they look after us when it comes to going away. I think it's important to mix with gay people because, you can freely speak I suppose. Like me saying we don't flaunt our sexuality with the community but when you're mixing with your own type, if you like, you speak freer.

Yesterday morning was a club meeting and talking to 100-odd people, and Greg put his hand up to ask a question. I've suddenly realised he's going to come out with something that could be taken the wrong way and I intervened. I actually had to explain to the speaker that Greg is my partner and a couple of the guys said to me later, "Hey, what's this mean about being your partner?"

Greg: I never flaunt myself. No, never have. I've always been reserved. I'm 77.

Kevin: Good boy, I was waiting to see if he'd remember.

Greg: I didn't associate myself with gay men because I come from the country and even though you know in the back of your mind you see someone walking down the street, the way they flaunt themselves, I'd say to myself, I'm glad I'm not them. Because I don't want myself exploited, I don't exhibit myself.

Kevin: In the last 23 years of our working life, it just coincided that we worked in the same business. There were a hell of a lot of gay people there and I used to have to mix with them but I didn't flaunt myself either but as we would say: it takes one to know one. I knew Greg's department well and had to deal with them but I knew Greg was frightened of being found out. I don't ever remember anyone in the organisation being persecuted and there were openly gays. There were definitely open gays. You know, everybody knew – I don't like to use that word, "flaunt," in the sense of putting a label on them but they were openly gay and they were accepted.

Greg's been assessed and we have a case manager who organises things and rings up regularly to see if I'm okay. Lately, the specialists that we're under interviewed me separately to Greg and then interviewed us together. He said to me he realised how long Greg's been diagnosed, and "You're lucky you've still got him because most of those patients have gone into care." From then on they seemed to be more oriented to making sure I'm okay.

We've got a package of care. The case manager always checks up. I get the periodical check-up. So what we get – I mean they won't tell you how much money has been allocated to you but what we get out of that, Greg and I have a respite day twice a week and he is picked up from home by taxi, driven to the respite house, he goes to that with a group of people. He's brought home at about three o'clock so I have that day to myself, that's covered by the package. Later in the week he's picked up by taxi and taken out to their day centre and then brought home again late afternoon. That's covered.

A cleaner comes into the house two hours every fortnight and vacuums, irons, cleans the showers and all that. That's what we're getting at the moment. It's normally the same lady that comes every time but there's the odd times when I've had to cancel and try and get another day. It's obvious to whoever comes to work through the house that Greg and I are sleeping in the same bed and all that. No questions asked, no problem, they joke with us, good with us, no problem at all.

It was interesting, our case manager we've had for quite a while - I took it for granted that she's put two and two together. Months ago, something came up, and I said, "you're obviously aware that Greg and I are gay," and she said then, "No, I wasn't." She said to me, "Well, when I first met you two it never entered my head that you might be gay." She was fine with it. She's also got somebody else that's gay I think, and I also know our home help lady has had to actually do cleaning for friends of ours who are gay.

I suppose one thing service providers need to know is treat LGBTI people with dementia as humans. Service providers shouldn't show any discrimination against gay people with dementia.

Questions for discussion

1. What reasons do Greg and Kevin give for not 'flaunting' their sexuality – and do you think heterosexuals encounter pressure not to flaunt their sexuality or relationships?
2. What does Greg describe as the importance of 'mixing with our own type'?
3. What impact has dementia had on Kevin's capacity to prevent disclosure of his sexuality?
4. Regarding disclosure of sexual orientation, what are the assumptions made by Greg and Kevin, and by the case manager?

Story 4: Gavin and Richard - Take us or leave us

We've been together nine years. Richard was diagnosed in 2008 but he'd been seeing the memory doctor for about 18 months before they said yes, it is Alzheimer's disease. They put him on medication, then after a while obviously as it sort of progressed it got to the stage where I was struggling to cope with it.

We've never come across any sort of bias or any kind of homophobia from service providers. Not explicitly anyway. You know, you never know what goes on behind your back but as far as I'm concerned take us or leave us, simple as that. I'm not afraid of standing up and being counted. But no, thankfully it hasn't really been an issue.

I had the aged care assessment done and they put me in touch with a range of services including the day centre activities. They said they would pick him up on the bus. I think that was twice a week last year and once a month on a Tuesday they have a lunch and drive out somewhere. So again that was about seven, eight hours a week I'd get respite and then the Tuesday once a month.

Richard loves it. Stick him in the car, go for a drive - because he liked his cars. He was always known in town because he used to have this old really old vintage car. And he used to have his dog on his lap driving around. And he had a Mercedes a few years back as well, a little hatchback, you know, one of those retractable roof things. It was lovely. So he loves driving.

If I was to describe my sexuality it would be homosexual. I'm not a great lover of the term gay. Gay is too trendy for me and a bit derogatory in a way, kind of. I much prefer the dictionary term I guess.

We've never had a problem with discrimination and we've had a number of different care staff. I kind of suspect that the service provider must tell staff beforehand. They must make them aware, that we are gay, a couple, and: "have you got any issues with that? If you have we won't put you with them". So I'm guessing they must screen for homophobia somehow, I would imagine. If they don't I've not come across any issues at all. I'm quite happy the way it is now.

To be honest I don't come into contact with any other LGBTI carers or people with dementia. I'm not a member of any carers groups. I did go to one, felt like a fish out of water, because a lot of them were heterosexual couples. I didn't feel awkward saying you know - I mean if it came up I'd say my partner and if they say 'oh how's she?' I'd go 'no, he'. You know - you're making the assumption and I'm correcting you, and if you don't like it that's your problem not mine, deal with it. I just thought this isn't for me.

We're having a bit of a battle with this relative over power of attorney. The relative wrote to the guardianship tribunal in response to my application for guardian. She's very conservative, quite pious. Anyway, she wrote to the tribunal to oppose my - not my health and welfare guardianship, she's quite happy for me to look after him - but the financial bit. So in her evidence she said "I'm only grateful that my children are of an appropriate sexual orientation".

I picked up on that, it is a bit homophobic. So you know I haven't taken it lying down. I find it very, very stressful writing my subsequent response to the tribunal, which was five pages long but there was lots of contradictions she'd made and judgments, gossip, and innuendo. It was stressful and until I sent it off my response, I would wake up during the night, it was constantly on my mind. It's just with you all the time.

"We're having a bit of a battle with this relative over power of attorney. The relative wrote to the guardianship tribunal and in her evidence said "I'm only grateful that my children are of an appropriate sexual orientation".

I'm of the view that I'm part of society and it should be you, the service provider, accepting me. I don't want to be separate, you know. I don't want to feel like there's something specifically for that group. I think there should be but I don't feel the need for it - but I know there are people who are more vulnerable than me.

I absolutely recognise that discrimination and homophobia is still a problem out there. I've never come across it myself from service providers, more so I think because possibly I've never been in that kind of situation. Because, we don't live an in your face kind of - we're camp as knickers queens, not that I've got a) a problem with that or b) you know it's an issue. It's not me and it's not Richard. I've never really come across any blatant homophobia, not to me anyway. Perhaps because they think I'd punch them in the face. Not quite but you get my drift.

Questions for discussion

1. What do you think are the derogatory connotations associated with the word gay (and how might these impact on service provider's values and beliefs)?
2. Do you think services screen for homophobic staff? (if so how?)
3. What could be done in the carers group (and other meetings and forums) to ensure they are inclusive of LGBT carers?
4. What difficulties were encountered by the family members' challenge to guardianship?

Story 5: Nick and George - Our natural selves

"I think George and I have been lucky because we're not outrageously gay. There's a lot of people out there that are and they are the ones that are going to find a lot of discrimination."

George: I was born in 1951. I just had a birthday and it was very nice. All my family, my sisters and everyone came and it was lovely.

Nick: And I was born in 1960. I'm gay. Definitely gay. We've been together for 37 years.

Nick: Like if you're looking at obstacles or anything like that we haven't come across any as yet. However, with your dementia cafes and everything like that, they are very heterosexual focused, very elderly focused. But then again they're during the week and George's not the sort of person who wants to go have a cake and a cup of tea.

You probably wouldn't mind something like if there was a workshop, say for instance creating things for the Mardi Gras floats or something like that, you know. Something with a group of gay people and just have a really good time and just create things and stuff like that.

Nick: We don't have much family over here. George's two sisters live over here. Heterosexuals, you know, they've got their family and they've got their children and grandchildren for support and everything, where as we have nothing. You know what I mean? We don't have that in our lives. And that can make it quite difficult, because we do have to rely on each other.

We've got some very good friends but I'm a bit of a stubborn person, I don't like to burden other people and things like that. Whereas we don't have a family. But we have some very good friends, we go out for dinner with them and you know catch up over the weekends and things like that.

George: Yeah, nice people and it's just, yeah, and we all have a good time and it's very nice.

Nick: This is going to be rather interesting because they are going to find us a housekeeper who's going to come in once a week. Now is she going to have a problem with us being gay? If we get any type of carer in, are they going to have a problem with us being gay? You know, that's a funny thing which I sort of never thought about. Obviously they wouldn't - maybe they train people to do a job and they just do it and do it well.

And is that person really like, against us, but they come in here because they get paid? We'd like to have someone who is acceptable and frank. We don't want to have to pussyfoot around and not be our natural selves sort of thing. It shouldn't be an issue - but then again could that happen? It could possibly, quite possible happen.

George: You don't know these days.

Nick: But I don't think anyone would have a problem with you, because you're a sweetie.

George: No, no, but you know, if you're out with family and people and everything, friends, and you get some people and they just don't want to see that, they want to cause some trouble. You know, it's unfortunate.

Nick: But anyway, that's society in itself still learning about things.

George: We haven't really had that but - - -

Nick: No, we haven't had that much. We've had a little bit of it though, but not much.

George: Some friends have had a few but yeah, no, it's good.

Nick: In a lot of services there is sort of that heterosexual kind of bias. If I would eventually need respite or an aged care facility for George, I believe that a lot of them are actually religiously run and there again they cater to the heterosexual who have got kids, grandchildren, things like that. Whereas George will probably feel comfortable in a place like that but it's still that stigma sort of thing, if they found out he was gay or something like that, you know. I would feel a bit worried about telling them we were gay if it's religious run. George is not religious at all and he wouldn't be entirely comfortable with all these people who love their church and all this sort of thing. I personally think George would go spare. If someone tries to press George, he'll lose his cool, sort of thing. If they sort of start preaching or something like that. I think George and I have been lucky because we're not outrageously gay, if you know what I mean? We're not really outrageous and not very camp in our actions and things like that. There's a lot of people out there that are and they are the ones that are going to find a lot of discrimination I think, you know. Some of these people are going to start coming through with dementia. Services can't really cope enough now, really can't they? So, I think they've got to start looking at expanding services to include gay people.

George: I've never seen anyone - I've never had any problems with anyone like that quite frankly.

Nick: I mean I don't think it's ever spoken about, is it?

George: No.

Nick: No one's ever mentioned about you being gay or anything on the trips?

George: No, no, no.

Nick: I think they have no idea. So look, leave it like that. If it works, well it works. It just hasn't come up. I mean there are times you don't have to be out, like you don't have to say it out loud. I mean as I said, because George and I are pretty straight gays if you know what I mean. Yeah, we're not really outrageous or out there, yeah, right in people's faces, "I'm gay, I'm gay". And I think that's why we fit into a lot of the norm. And no one sort of questions, you know. Whereas if George was a bit more camp or something like that, you know, someone would probably say "Are you one of those poofters" or something like that.

George: I'd probably do it the wrong way.

Questions for discussion

1. What do you think 'being our natural selves' means?
2. How could home care service providers send a message to George and Nick that it was safe to be their 'natural selves'?
3. How would staff in your service respond if George and Nick's relationship was revealed?
4. What do you think a 'heterosexual bias' means and how might this relate to the lack of relevance to the activities in mainstream respite programs?

Story 6: Tim and Phillip - Somewhere fully nice

I was born in 1941 and my partner Phillip in 1943. We were together 25 years. We describe ourselves as gay. He went to the memory clinic in 2003 and was diagnosed with depression causing memory loss. In 2006 he was diagnosed with Alzheimer's; 2007 with Parkinson's. Then I was warned it was probably going to be Lewy Bodies, but we had to wait till 2011 before the hallucinations appeared. Once they came, staying at home wasn't an option. He went into care in 2011.

"The place we found was very, very friendly. I knew that the minute I walked in there. The care manager didn't bat an eyelid when I told him we were gay and in a relationship."

My policy from square one was to risk everything until something went wrong. And it never did. During the time between the diagnosis for Alzheimer's and for Lewy Bodies, we went on 15 cruises. Doing exactly what we were doing, making the best of the last final years together.

I think if you can find a nursing home which has no problem with sexual orientation, then you have no problem. And there are a number of older gays - because they were brought up in very difficult circumstances, who sort of go back in the closet. I do know one or two who sort of, to me, tend to be very guarded and straight, and all the rest of it.

I think gay people with dementia go back in time. Phillip did. I'd give him a kiss and it wouldn't worry him, and things like that. He was sort of closeted 50/50. If he had to make the decision about who to disclose sexual orientation to, it probably would be a closeted one. Occasionally he'd sort of say, "Oh, you don't need to tell them about our relationship", or something like that. And I'd say, "Well, sorry, I'd just forgotten to do that". And he'd sort of laugh and say, "Okay".

When Phillip was in hospital we had to find a nursing home for him. In one facility when I mentioned 'partner' suddenly they were apologising that the carpet was going to be taken up and "it might be very difficult" to admit Phillip. And I thought, thank you; the message is loud and clear.

There was another facility that rang me up and said she'd looked at the report, and he was a bit aggressive, and they only had nice dementia patients.

As soon as those things cropped up, I just rejected the facility. I just thought, what's the point? There's no point. And I would just say to the hospital, "Well he's staying in that ward until you help me find somewhere where they're nice to me". Fully nice.

The place we found was very, very friendly. I knew that the minute I walked in there, I have no complaints against them at all. It was old but there was a very deep, caring feeling about the whole place the minute you walked in. The care manager didn't bat an eyelid when I told him we were gay and in a relationship.

We just knew what it was like, and it was a very, very pleasant place. The staff were pleasant. Being gay didn't matter. In fact they thought it was rather nice to have a gay couple there. They were always just lovely, because you know, we'd go out for a walk, and to get past reception it would take us 15 minutes - they'd be fussing after him.

I took Phillip out of the facility five days a week for two and a half years - never missed, except when it was pouring with rain and when I went away on holiday once. I went away for a week.

I didn't have a support network. Friends were hopeless at going in there to visit him and I can't blame them. I mean at the end, it used to irritate me that they didn't go in to see him. They were very good when he was at home, but only two went in to see him in the facility. It's not unusual. At the end of the day, I can't blame these people.

I think the needs of carers should be a priority. I do feel that carers need a lot more education before their partners go into care. I think basically the industry's done very well at the beginning, but not done so well at the end stages of dementia. Or the care - post carer stuff. You don't realise the damage you're doing to yourself. I was told by the doctor, "You'll be physically and mentally paying for all your care", but I didn't realise it was going to be in such a way that I have. And I have suffered for it since. The month after Phillip died I was in hospital with very bad eczema and cellulitis of both legs. And that was really down to stress.

I think aged care service providers need to work with all people with dementia. And they probably do need some special education, maybe about LGBTI people. Or you need to have people in those jobs who are a bit open minded.

Questions for discussion

1. What does 'fully nice' means in relation to LGBT inclusive dementia services?
2. What do you think a service could do to communicate 'the minute an LGBT person walks in' that they are LGBT inclusive?
3. What impact could one person's perceived want to closet have on their same sex partner?
4. What could you do to support the carer including in their time of grief?

Story 7: Jeremy - If I could go out the front door ...

"Service providers have just got to be understanding."

I'm 47 and I got HIV. The doctor that diagnosed me with HIV is heterosexual and married with children and he's a friend of mine, and like he's good, he's been good. He's been my mother's doctor for years and my grandma's doctor for years. My father's doctor, been a family doctor.

My mum's good. My father's understanding to a point but he's not quite as open - he's not quite as accepting as what my mother is and ironically enough my mother's religious and my father's not religious, so I guess that says something about religion.

My mum wasn't good when I first came out. She went through my porno collection and found them all and went through a ritual thing like that and I rebelled against that. But, you know, I don't really - that sort of thing doesn't appeal to me anymore. When I was a teenager it did, more than what it does now.

Up in the city one night, I went up to the Seven Eleven and got a coffee and got some money out and bought a packet of cigarettes, and got robbed and bashed. They stole a gold chain and a ring and nearly murdered me. They took my car keys.

They got the CCTV footage and they got the two guys that did it but they were out on parole and they didn't get much, they only got 18 months gaol for what they did, which I thought was pretty crumby.

I moved to a residential place for people living with HIV. When I was at there one of the professors said "we think that you might have early onset dementia". I can notice it but I don't think that it's affecting me badly at the moment.

I liked that place. That was good, I liked it there. I had my own apartment and I had my own bathroom and I had a lot more freedom than what I've got here.

Now I'm in a residential place at a hospital. I used to be able to go out to the nightclubs and everything. Whereas here I can't - I don't get to go out and do much of what I want to do. It's because it's a hospital facility and like I couldn't say "oh let's go up to a shopping centre now and have a coffee". They wouldn't let me go - like, they'd let me go but they wouldn't let me go by myself. And I find that disheartening.

If could get out and go to the Beach for a day, I'd love to do that. Not because I want to go and perve just because I just - I like getting the sun and I like to skinny dip.

I'd like to go to the beach and sunbake one day. In the afternoon at 12 o'clock they have lunch time special but I can't get in there to do that because there's no public transport from here, and I can't drive at the moment because they've taken my driving privileges off me.

I went to the beach the other day and I got a bucket of prawns. But I went with the guys from the house and because there were so many of us and because so many of them incapacitated, they couldn't go to the beach and they couldn't do this and they couldn't do that and it was like bummer.

Well if I need to go shopping I'd like them to take me shopping. I can only talk for a certain amount of time before I get too tired to talk, you know. And I just sort of run out things to say.

My mum takes me back home every fortnight. I'd do everything that I could to get out of where I was. While I'm happy enough as it is here, I often feel like just taking off and if I could go out the front door I would. I spent the whole weekend here and I didn't get to even go outside at all.

I've got one friend in here. I wouldn't say he's a good friend but at least he's sympathetic to me and I think he likes me. I don't suffer fools gladly, you know, and I can be quite temperamental.

Service providers have just got to be understanding. Tolerant and understanding.

Questions for discussion

1. How does Jeremy describe his historical experiences of disclosing to his parents?
2. How important are Jeremy's social connections and how could you assist in facilitating these?
3. How important is it for him to get out of the facility and how could this be accommodated?
4. What do you believe are some of the issues for an LGBT person living with dementia "going it alone"?
5. Thinking about co-morbidities, what do you believe the care needs are for someone living with HIV and dementia?

Story 8: Geoff and Dave - Not being different

"Without the carers support groups I'd be lost and I think a lot of other people would be."

I'm Geoff. I'm 62. Dave is 65. We've been together now for 34 years.

Dave seemed to be different when we came back from a trip. He seemed very edgy waiting for his bags, irritated and he looked quite worried they weren't going to come out. He seemed a little bit meeker - not meeker but just that if he did something wrong and if I snapped at him he would normally snap at me but he said, "Sorry, sorry".

So it probably goes back to late 2009 and then after that I didn't feel things were quite working right and then he retired. It was a year later the doctor said, "Do you mind if I send you for some scans, just to make sure there's nothing there", and that's when they found the atrophy in the frontal lobe. And then when he did the test and he said it was Younger Onset Dementia.

But as I say it's been - luckily with Dave's condition it's quite passive. Dave's quite happy here. We might go for walk, then we go and have a sleep on the bed.

At the moment Dave's still okay on his own, I haven't got to the point where I need respite or carers but I know where I can go. I don't feel like I'm suddenly in a hole and I've got to try to dig my way out. I've got other people around and contacts and I'll see if I need respite care, things like that.

I keep things in perspective by thinking how would Dave cope if we never met? Say we'd never met and he just lived a single life as you know a lot of people are still single. How do they manage? How do they manage?

We call ourselves straight gays. Other people when they see us they've said unless you would have told us we wouldn't have known you were gay. I said you get the different types, you know. I said you get the people that are over the top, quite effeminate, but I said it's amazing how many friends that we have. Like we've probably got more heterosexual friends than gay friends but you wouldn't know there is a difference. I could probably point people out to you and you wouldn't say they were gay. That's what I call straight gays.

You get all the different classes but I don't see myself any different to any other gay or any other hetero or anything.

I've always been honest with people when I've gone for a job. In one job interview I can't remember how it came up and I just said yes, I'm with my partner Dave, I said, it's a gay relationship but it's very close and nobody seems to bat an eyelid.

When I first came out, it was mum first and I said to her tell dad later when you're together and when I rang mum a week later she was quite upset and she said things that really hurt. It was just before Christmas. So I rang a couple of days later and dad answered the phone and I thought oh God. But no, he said, "That was your mother's emotions speaking", he said, "You'll have to excuse her, we grew up in a different era" and this, that and the other, he said, "We've never been a family to sweep things under the carpet, if we don't face it now we never will". And then he said, "Well you'd better both come down for Christmas" he said, "We've already got Dave's Christmas present". So from that Christmas everything seemed to work out very well.

Without the carers support groups I'd be lost and I think a lot of other people would be. It's not as though it's a cure, it's just something to ease the burden. And just talking to somebody just lets a lot out and you feel a lot better when you realise you're not alone. They all know. Everybody knows and I've made some good friends in the carers groups and you know they all know about Dave, and I think most of them say oh yeah, most marriages don't last 34 years.

I know where I stand, but if I can keep Dave as long as I can but then some people said even with a live-in carer he may need more urgent attention that you can't do with home care. But then if you've got a live-in nurse, you don't know.

I think people who are kind of overtly gay, they feel a lot more confident in themselves, because they show how they feel rather than somebody who might be a straight gay but wants to be like that and is all mixed up and doesn't know which way to go. Anybody who goes in the gay Mardi Gras, it's all open there and they're the kind of people that I don't think it would really matter to them if they experienced homophobia. But a lot of them, just because they are gay, may prefer to have a gay health service.

You want to make sure you get the right responses from service providers, knowing that people are doing the right thing for you. Not because you're gay or you're Chinese or French.

Questions for discussion

1. What do you believe might be the impacts of being 'straight gays' in receiving dementia care services?
2. What do you think Geoff means by "you want to make sure you get the right responses from services providers, knowing that people are doing the right thing for you", and particularly in relation to providing care for LGBT people living with dementia?
3. Geoff was open with people about his sexual orientation both in work situations and in the carers group. Thinking about your service, what response would he receive from your service and staff if he disclosed their relationship?
4. Geoff "wants to keep" Dave as long as he can. In what ways could he feel more supported and confident to access support services including your service?

Story 9: Lynda and Veda - A red and black angry sky

"I worry about LGBTI people with dementia who live alone. Who is their advocate, you know?"

Veda loves life but she also lives with that thing of 'God I'm sick of putting on a happy face', you know. She has moments of deep sorrow and terrible fears. Six years ago, before her diagnosis of dementia, she was diagnosed with anxiety and moderate depression. She feels deeply. She was diagnosed with a rare form of dementia (young onset fronto-temporal dementia/logopenic progressive aphasia or FTD/LPA) more than 3 years ago at the age of 61. She's a retired rock musician and a lifelong member of APRA as a songwriter, but she's losing verbal language and can't find the words to express what she feels and thinks... she's lost her "voice", her art. About 2 years after her diagnosis she went through some really horrendous panic attacks every morning for about a month. I've done senior first aid, but there was no way I could help her with those attacks. She couldn't hold a coffee cup, was bent over double, shaking uncontrollably. It was terrifying for her.

One day I picked her up from her art class (where she'd been going for a while, quite happily) and found her very upset. Maybe it was due to the fact that the other students had been doing art for quite a long time, whereas it was a new artistic medium for her. Maybe it was the music playing that day, but she ended up in tears and said "I'm never going back". She was so upset that day that she couldn't express how she felt and was quite panicky and very shut off. But she's also a photographer and she'd taken a lot of photos of skies, some of which she was very proud of. I had her notepad with me in the car, so I drove her up to look over the sea and pulled up the photos, flipped through a few and, after she'd had a cigarette to calm down, I said "Are there any photos that reflect how you feel now?" She just pointed out this red and black angry sky. And I said "Right, fair enough" because I'd been waiting for her to get angry.

The dementia experience is very different for us lesbians.

We have gay, lesbian and straight friends in this area and they're very good friends, they're exceptional in the way they deal with Veda. They understand what's going on and they're completely there and they assist her, they support her, without ever taking over from her. However, some of her oldest friends can't deal with it. They just can't. It's such a shock.

One of them said "She can't even get her own coffee!" I thought 'Well, I did send you an email, I did have that conversation with you - and you're here for just one night'. All this friend could do was get drunk and talk loudly about her life. And I thought 'Wow, you're one of my supposed backups if something happens to me, whoa'.

Veda and I have met quite a few people with dementia in our local area (Illawarra). It's been interesting for us to interact with them quite openly. There are people who are very conservative church members ... and it's interesting for them to hear that our circumstances are different. We don't have a daughter or a daughter-in-law who's going to give up one day a week for the rest of however long to give us a break, you know. It doesn't work like that. We don't have anyone who can or has offered to come and help out regularly.

When things have been hard it would've helped me enormously to have someone who knows about dementia that I could call and talk to at any time. And if that person were LGBTI, even if it were a gay man or a trans person, I would find that easier than talking with someone who assumes the family background. Isolation issues are exacerbated as we know for LGBTI people living in regional areas who generally speaking encounter a lot of homophobia. I wonder if we would have more support from our community if we still lived in the city.

It really concerns me that other people with dementia who are LGBTI may have families who do not accept their life situation: they are going to be really under the thumb legally because of that.

I worry about LGBTI people with dementia who live alone. Who is their advocate, you know? Unless you have someone who is a really close friend... and then, not many people have enough experience in being the care partner or the supporter or the advocate to even start to know if they can do it. Let alone knowing something about dementia or being prepared to learn...

I really don't know how LGBTI people living alone, particularly living alone in remote regional areas without at least some LGBTI people around them, would be able to die in dignity. I really don't. I just - it breaks my heart. They are terribly vulnerable. Terribly.

I have always been out in my lesbian life but Veda wasn't when she was quite young, no way. When she first moved here she wasn't comfortable with me holding her hand walking down the street because she expected to be beaten up, because that was how it was in the 60s in her home city, right? But she's embraced life here and her own residual inhibitions have now lifted as a result of her dementia, which is quite liberating for her.

I think a lot of people have the miscomprehension that people as they age lose their sexual interest. And there would be a lot of people who have been taught that people with dementia don't feel pain.

When Veda first saw you, she knew you were a dyke - she immediately went and hugged you. Five years ago she would've probably hugged you when you left but not when you first arrived. But because she has dementia she's not as aware of social conventions as she used to be, which is interesting. So if she were to hug a female care worker and the female worker knew that she was a dyke and couldn't deal with that, okay, how does the worker react?

This is an important scenario that service providers could discuss. Are you actually as a care worker, going to push that person away? No, of course you're not. And what if they plant a kiss on your neck, then what will you do? How will you actually deal with it realistically? Veda's particular diagnosis makes it harder for her at this stage than for some other people with different dementias, because she has less verbal language to draw on. But she's also much more expressive.

Questions for discussion

1. What does Lynda describe as the importance of connecting with LGBT people?
2. Why does Lynda think LGBT people with dementia are vulnerable?
3. How would you respond if Veda hugged and kissed you when you visited to provide services?
4. Would your responses to Veda be different to your responses to a heterosexual woman?

Story 10: Maurice and Collin - If you don't understand - ask me

"We want people to respect our relationship. We want people to understand our relationship."

Collin: I describe myself as a gay. I think I would describe Maurice more as a homosexual man.

Maurice: Well, gay is a word that doesn't have much meaning for me. My sexuality came up on me when I was very much a grown up person. And it's not something that I knew about from when I was young. So it doesn't have that much meaning to me. I mean, wouldn't use it myself.

Collin: Maurice's dementia was diagnosed in 2006 I think.

Maurice: So 2006 would be nine years ago, would it? I knew I had AIDS and stuff, earlier than that. I mean, it's not very easy to tell these sort of things. The AIDS thing started earlier.

Collin: Maurice has a sister and a brother - his homosexuality is tolerated but not necessarily accepted. Our relationship is not understood or accepted. I am seen as a financial predator by some of Maurice's relatives. It has been at times a difficult relationship. Maurice doesn't care about the conflict because he forgets about it and Maurice is incredibly conflict adverse, so he will just rather say yes and put up with whatever rather than conflict.

Maurice: They can do what they like. They can do what they like. It doesn't affect me. If they choose to behave like arseholes, well, that's their problem.

Collin: Unfortunately the only person that is likely to come to his aid is his sister. Yes, she comes from a good space, but she also would do so in order to control. And that is what she did when she was Maurice's power of attorney. She wanted to have things done her way, which unfortunately is not the way Maurice would like his life to be directed and which puts me in an awkward position. We don't have anyone that I feel comfortable leaving Maurice in their care. I haven't been away in six years. We haven't been on holidays in six years either. I've only just made contact with the local carer support group here. I think through accessing the groups I was able to look at some of the more practical issues.

Maurice: This is my best support group (cuddling his dog). He's gorgeous.

Collin: He is. And he's been wonderful for Maurice. I think we live a very sedentary life, there are no children here for example. And so my concern is to organise some ongoing carers that Maurice is going to accept. Because he doesn't want – what did you call it? "I don't want a well-meaning lady to be a pleasant nurse or something", Well, that may happen at some point that we need in home support.

Maurice: Well, I mean, if that's what they want to do and whatever is good for me, that's fine.

Collin: It might be what you need though. Like Maurice I also live with HIV and diabetes type 2 and other issues, so I also have to rest.

Maurice: But, I mean, are these constant concerns to you?

Collin: They are sometimes, darling. I mean, you don't see; you also make absolutely no plans and unfortunately that is a problem that you're not going to have to live with because by the time it becomes a problem you are likely not to be in a state where you'll realise it is a problem and I'm going to have to deal with it. I think that where Maurice is concerned in the future if he ever does need care here we need to have somebody that actually understands what it is like for two gay men to live together and understand that that is - preferences – this is natural.

Maurice: Why is this a problem?

Collin: Well, some people don't have that understanding - at some point he needs to go into an aged care facility, he may not be very conscious of what's around - but it will be a problem for me if I don't see him being well treated. Or if I am not respected as his partner in the process and I've seen that all too often with the very early days of the AIDS epidemic. We were not recognised as being somebody's partner and having the right to actually make decisions over the family who may have been estranged for many years. Family who in the last steps say, "Well, we're his next of kin so we will decide what happens here". I've seen those conflicts and they're not pretty and you don't need them.

Maurice: I think the effect of dementia on sexual orientation is vastly over simplified, and I don't think that's the case at all of losing your sexual orientation. I mean, look, I'm less sexual I suppose but that's about it.

Collin: Yes, but I think also that's partly age too. I mean, it is a bit of an ego thing to find that your partner doesn't remember when you're having sex twice a day. But, you know, once you get over that then that's fine because that's the way it happens.

Maurice: It's not that I'm a dud.

Collin: I don't know that people become asexual. I don't know whether it's choice or circumstance because there's a combination of things, you know. We want people to respect our relationship. We want people to understand our relationship.

Maurice: So I don't actually have a lot of experience with people like that but, I mean, I don't think I've ever had a bad relationship with a nurse or a service provider.

Collin: I have an expectation that we would be respected as individuals and as a couple and that our choices would be respected. I won't let people boss me around. So my expectation is that they do respect what is there, and if they don't understand it - ask. I would like people to see that – they're still dealing with another human being that may have a different background or a different story to what they are used to and that if they don't understand I have an expectation that they ask.

Questions for discussion

1. How might the earlier experiences in the AIDS epidemic have shaped their current perceptions of aged care?
2. What concerns do Maurice and Collin have about accessing services, and how might your service be able to alleviate these concerns?
3. How might the issues with Maurice's family influence decisions made about Maurice's care?
4. How can we ensure the onus of responsibility regarding education is placed on the service provider and not on Collin or Maurice?

Story 11: Edna - For Harvey, he's a woman not a man

Edna is in her 80s and living with dementia in a residential aged care facility. Edna transitioned from male to female in the 1970s. Edna was married at the time and had two children. While her wife and daughter accepted her as a woman, her son did not. When Edna was admitted into an aged care facility following a stay in hospital, she appeared as a man called Harvey. Edna's story was told by the residential aged care service where she lived.

The reason why this gentleman, Harvey, is living as a male here is because the son said, "If you don't - if you embarrass us and you don't dress like a man, you won't see any grandchildren."

We really didn't know a lot about this gentleman before he came in. We found out on the paperwork. When he came in. And, um, one of the staff went to assist him and got a terrible shock that - I'm saying "him" because that's the way he's living at the moment. He had a gender reassignment in 1975 from male to female. Quite a long time ago. And when the nurse was toileting him she noticed that his anatomy was different. And he just - he told her what it was all about.

She nearly fell over. She really got a shock and I'd been reading the paperwork anyway, by this time, when the nurse came to me. The paperwork was pretty clinical, it just said that he'd had the "gender reassignment". So then we start putting things together ourselves. The rest of the staff were informed and took it from there. There's been no issues whatsoever about his situation.

As far as the staff go, he's settled in well. His dementia has progressed now... but he actually lives here as a male. Dresses as a male. He blends in quite well. A very nice person. If you look closely you may think there's something a bit different because he doesn't grow facial hair. One of the other residents - one day I thought we were going to have a bit of a problem because one of the other residents apparently called him a "Sissy." He was going to knock him out but this other gentleman - it wasn't because he recognised anything - it was just that something that this resident had said, to this old ocker Aussie - so - thank God, so there's been nothing. But that's - I think that's just personality, you know. Because they're on a table that's all men. Our biggest issues have been the family.

The children were only early teens at the time of Edna's transition, and they're having problems adjusting - still 40 years later. The reason why this gentleman, Harvey, is living as a male here is because the son said, "If you don't - if you embarrass us and you don't dress like a man, you won't see any grandchildren." So that's why he's living as a male here. Not that the son brings his children in much, but that threat was made. And there's issues over money and that's very distressing for Edna. So the biggest impact has been the family towards him. Not the staff or other residents.

So you can see this time and what the family has been through is impacting on this poor man who can't be who he wants to be. And that's the biggest - I think that's the saddest thing. Prior to him coming - or being admitted here, he was living as a female. Dressing as a female. The only thing you might pick up on here is when he goes out, his bag that he takes with him is a lady's bag. But it's not overtly a lady's bag, but it is a lady's bag. So coming here has been a change - gone full circle back to - But not of his own choice. But he's accepted it. Because he wants his family. It's very sad. I think the issues though, have impacted on his dementia - Family issues.

He handled it better than the nurse did. Because to him, I think, it was probable that he's come across this several times. We don't question Harvey about it. If he wants to tell us stuff he does. And, he will talk from time to time, not so much now because of his dementia. That's been quite positive from - I mean, not that we wouldn't provide the resources or the training, but it hasn't been one that would fit in with the need, so - Even with Harvey's dementia I think, you know, it's a positive experience that it hasn't impacted on the care that is provided to him.

And - and he would've blended in as a female. This person, himself, as an individual. It wouldn't have been an issue. It was only the family. I mean this is specifically for our organisation, we don't see it as a challenge. I mean, there's always challenges with everything. But different residents have different challenges. It will just be, a different type of a challenge but I think, from a service provider, with the right attitude, and the right approach then, it's providing a home for individuals to identify as trans. That is male to female - female to male, I think is very much achievable. And individuals, should feel safe that they will be looked after. And not ridiculed. And as we're saying, in reality, and you're always going to get individuals, I think this has been a positive experience so far. It would've been interesting to see if Harvey had, you know, come here as the gender he's chosen to be, and what reaction - That's the saddest part - We would get.

I'm hoping people don't have to go down that path but if Harvey decided one day that, you know, with dementia advancing and it gets to the point where he says, "You know what? I don't care what they say any more - this is who I actually am." He does, I don't know, maybe I imagine it, but with his dementia and in those little periods where he's really stressed with the family, he is more female than male. He would express himself more openly, be weepy and need that tactile, and a bit more emotional, I mean, that could be stereotyped. For Harvey, he's a woman not a man. I don't think he just woke up one morning and said, "I want to be a female" so he's probably had this all his life. He's a huggy, feely sort of person. When he's distressed it breaks down that façade that he has to put on here of pretending to be a man.

I can guarantee you I wouldn't have said no to him, or her - either way he or she - chose to live. Or I think given the information beforehand, because I meet people as much as possible before they come in. But in situations where there's delicate information like this, you just do a bit of staff education and we talk to residents when we're having our resident meeting, every now and then we'd bring up respect for each other and acceptance and things like that, but staff education would help if we had proper communication.

And again, right now we can't do more than what we're doing right now. And we are managing our situations and we don't believe that these individuals are being treated in any less than what others are in terms of respect and dignity and so forth and probably the more that we can do for these individuals – but at the same time I don't know if Edna's missing out or they're being restricted of living the life that they chose to and what not, so far I think we've done well within the policies and the means and the family. I think we just need to be open. Be open to things and not be so scared. Because I think a lot of people get scared. Because it's something they're not familiar with. Like anything else.

Questions for discussion

1. Do you believe Edna's rights have been violated? (by whom and which rights)
2. What do you think is the impact for Edna on her inability to live as a woman?
3. How could your service advocate to ensure Edna's rights to gender identity were respected?
4. What services could be accessed to assist Edna assert her rights?

Section 4: Resources and further information

Val's Café

Val's Café was established in 2009, and seeks to improve the health, wellbeing and visibility of older LGBTI Australians. Val's Café is part of the Sexual Health and Ageing program at the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University, Melbourne. Val's Café conducts research, develops evidenced-based resources, and advocates on behalf of the needs of older LGBTI Australians. Val's Café works directly with stakeholders and service providers to foster an understanding of the histories, experiences and needs of older LGBTI people, and to build the capacity of services to be LGBTI inclusive. Central to the work of Val's Café is research which is privileged by the voices of LGBTI people. From this research, Val's Café develops evidenced-based resources to help inform the development of LGBTI inclusive services. Visit Val's Café website to access information and resources, become a Val's Café member - membership is free and provides access to regular newsletters and information bulletins.

Website: valscafe.org.au  @ValsCafe_AU  facebook.com/ValsCafeAus

Alzheimer's Australia

Alzheimer's Australia represent the more than 342,800 Australians living with dementia and the estimated 1.2 million Australians involved in their care. Alzheimer's Australia advocates for the needs of people living with all types of dementia, and for their families and carers, and provide support services, education and information. Alzheimer's Australia also represents, at the national level, the interests of its federation of state and territory members on all matters relating to dementia and carer issues. Alzheimer's Australia is committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

Website: fightdementia.org.au

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